Title: Co-production and pilot of a structured interview using Talking Mats® to survey the television viewing habits and preferences of adults and young people with learning disabilities.

Running title: Co-production and pilot of a Talking Mats® interview

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Accessible Summary

* We wanted to find out what people with learning disabilities think about watching television.
* Some people find it difficult to say what they are thinking.
* We worked with ten adults with learning disabilities who helped us find the right words, questions and pictures to use in our Talking Mats® about watching television.
* We tried out the questions on five people to see if our Talking Mats® helped them to say what they thought about television. We made some changes so that the Talking Mats® were ready to use with lots of people.

Summary

Background: Capturing the views of people with learning disabilities is not straightforward. Talking Mats® has been used successfully to solicit the views of such individuals. The aim was to co-produce an interview schedule using Talking Mats® on the subject of television viewing habits and preferences of adults and young people with learning disabilities. A secondary aim was to assess the feasibility of the tool prior to a larger scale survey.

Materials and Methods: A co-production process was adopted for the development of the Talking Mats ® interview. Ten adults with learning disabilities were recruited as collaborators. Six people participated in an advisory group that met on six occasions. Four supplementary members reviewed the group's work separately. The collaborators generated vocabulary for the tool, selected the most meaningful graphic symbols and reviewed the categories of television programmes. A script to accompany the Talking Mats® procedure was developed and checked for linguistic complexity. The resulting tool was piloted with five participants. The procedure was video recorded and evaluated for procedural effectiveness.

Findings: Review of the video recordings from the pilot study revealed that no participant scored below the minimum effectiveness rating of 12. Areas of difficulty that were noted included: time duration of interview, tangibility of symbols and currency of vocabulary. These triggered a number of recommendations for address in the larger scale survey.

Conclusions: Working with people with learning disabilities as collaborators helped to develop a tool fit for purpose.

Key words: co-production; interview; Talking Mats®; graphic-representations; linguistic analysis.

**Introduction**

The value of listening to the views of service users has long been recognised by providers and managers of services, wishing to evaluate the quality of their offering, as well as researchers investigating the views of particular sections of the population on a range of topics (e.g. Law et al. 2005; Lewis 2002; 2004). The opinions of people with learning disabilities are no less important than other people in society. However, capturing their views is challenged by the presence of speech, language and communication problems (Bunning 2011), limited or non-existent literacy skills (Jones *et al*. 2006; Verhoeven & Vermeer 2006) and poor working memory (Abudarham 2002). There is a tendency towards suggestibility and a desire to please (Baxter, 2005). Furthermore, low self-esteem may affect individual ability to articulate thoughts and ideas, as well as difficulties with open question formats, extrapolating from personal experiences and reflecting in abstract ways (Clarke *et al*. 2005).

Having a significant other present, e.g. parent, carer or paid keyworker, has been used to circumvent such difficulties in an interview situation, providing both psychological and practical support (Law *et al*. 2005). The majority of the people with learning disabilities in Emerson et al’s large-scale survey (2005) had a carer present, with approximately 31% acting as the main respondent in the interviews. Use of a proxy spokesperson can be helpful when the respondent has severe cognitive and/or communicative difficulties, e.g. providing prompts to enable the person to respond, sharing relevant insights based on experiential knowledge of the person and supporting the interaction generally. However, other problems may ensue. Baxter (2005) observed a tendency amongst carers to dominate the interaction and Buttimer and Tierney (2005) reported discrepancies between informant responses to the same questions.

In the context of these challenges, particularly for individuals with restricted communication skills, the need for structured support has been recognised (Lewis *et al*. 2008). Talking Mats® offers a potential way of enabling people to express their views. Through use of visual media it provides alternative ways to present meanings and concepts in an interview situation, so there is a reduced reliance on spoken verbal communication. It employs a visual framework of pictorial symbols to represent topics and options, which are evaluated through use of a pictorial scale (Cameron & Murphy 2002). Widely used with people with learning disabilities, Talking Mats® has been used to facilitate decision-making and self-expression (e.g. Ajodhia-Andrews & Berman 2009; Bell & Cameron 2007; Bunning *et al*. 2009; Cameron & Murphy 2002; Murphy & Cameron 2008). Reported benefits include a reduction in acquiescence through the provision of meaningful options (Cameron & Murphy 2002; Whitehurst 2006), enhancement of understanding between interviewer and respondent (Brewster 2004; Murphy & Cameron 2008), and opportunity for participant validation – a core principle of qualitative research (Nind 2008). Flexibility is built into the procedure such that the number of items in the rating scale may be altered to cater for differing cognitive abilities (e.g. Bunning *et al*. 2009; Cameron & Murphy 2002).

**Co-production**

Ensuring a data collection procedure is ‘fit for purpose’ necessitates a deliberate approach to its development. Co-production is a mechanism for actively involving people who are the direct beneficiaries of a service, product or piece of research. It aims to work with communities, offering opportunities to shape the development process, thereby ensuring a relevant outcome (Durose *et al*. 2012).

Recently, the involvement of ‘hard-to-reach’ groups, which includes people with disabilities, has been promoted in health and social research. Durose *et al*. (2012) identified seven key dimensions of the co-production process: presence, interactive knowledge production, inter-disciplinary participatory research traditions, public value, authenticity, reflexivity and beyond-text. The core principles of ‘presence’ and ‘interactive knowledge production’ help to ensure representation of the user perspective and development of a shared dialogue respectively (Durose *et al*. 2012). ‘Inter-disciplinary participatory research traditions’ provide some useful guidance in the quest for engagement with participants of research. Co-production extends this dialogical approach to one that aspires to be transformative, such that there are opportunities to shape and change the research agenda (Robinson & Tansey 2006). The principles of ‘public value’ and ‘authenticity’ consider the legitimacy of research endeavours and the inclusion of relevant expertise. In this way, members of a potential beneficiary group contribute to proposal development from early definition of the problem situation to decision-making about methodological procedure.

‘Reflexivity’ infers the importance of reciprocal dialogue and the potential for mutual influence between different members of a research group, regardless of designation. Thus the person with expertise borne of the lived experience works collaboratively with the researcher. Since the 1980’s, there has been increasing interest in this type of collaborative practice in health and social services (Hibbard *et al*. 2007). Both the provider and user bring their motivations, knowledge and experience to the table so that services are shaped and refined (Windrum 2014). This requires a shift in the role performed by the practitioner from ‘fixers of problems to facilitators who find solutions by working with their clients’ (Realpe & Wallace 2010; p.5). The power in the user-provider relationship is redistributed so that there is mutual recognition of expertise (Boyle *et al*. 2006a). The involvement of people with learning disabilities in research design has been linked to accessibility and empowerment by a number of researchers (e.g. Brewster 2004; Cameron & Murphy 2002; Rabiee *et al*. 2004; Whitehurst 2006). However, difficulties may arise for adults with learning disabilities in the generation of ideas or analysis of concepts associated with a task (Brewster 2004). There is emerging use of beyond-text tools in research, e.g. through narrative, various art forms and dramatic performance (Purcell 2009). These methods enable the visualisation of core concepts associated with the field of study (Durose *et al*. 2012).

People with learning disabilities have been involved in a variety of shared tasks, such as literature reviews, peer groups and observation of participants. For their national survey of the lives of people with learning disabilities, Emerson *et al* (2005) determined the questions that needed to be asked by speaking to people with learning disabilities and their supporters. The final set of questions comprised closed formats requiring a yes/no response, multiple choice-style responses and some more complicated questions. People with learning disabilities were also involved in training the interviewers to ensure respondent participation. Vocabulary selection is integral to an accessible, functional and meaningful Talking Mats® interview. Some researchers have employed people with learning disabilities as informants in this process (e.g. Brewster 2004; Cameron & Murphy 2002; Murphy & Cameron 2008). Ajodhia-Andrews & Berman (2009) combined professional opinion with third party advice, whilst Rabiee *et al*. (2004) used a linguistically more able population to inform their study.

**Research Aim and Questions**

We wanted to develop a structured interview tool that would facilitate people with learning disabilities to be the primary respondent in a survey of their television-viewing habits and preferences. Television as a leisure activity was selected for its popularity in mainstream society (BARB 2011-4) and as the most commonly reported communication service used by people with learning disabilities (Ofcom 2008). In keeping with the idea of research *with,* rather than research *on,* and to ensure the relevance of the structured, interview tool, the aim was to follow an inclusive, development process that would involve people with learning disabilities as collaborators.

There were two main research questions:

1. How are people with intellectual disability able to contribute to the development of a survey tool such as a Talking Mats® Television-based interview?
2. How effective is the Talking Mats® Television-based interview?

**Methods & Materials**

Co-production was used in the development of a Talking Mats® interview for surveying the television watching habits and preferences of adults and young people with learning disabilities. Ten people with learning disabilities acted as collaborators through membership of a Talking Mats® Advisory Group (TAG), six people being core members who attended regular, group meetings, and four people acting in a supplementary capacity who attended one-off meetings either singly or in pairs. The development work was split over two settings: a day centre for adults with learning disabilities in the age 40-50 years range where the core membership was established, and a respite care facility used by younger adults (25-40 years) for the supplementary membership. Following the development of the Talking Mats® interview, a small pilot study was conducted to check its feasibility.

Ethics and Recruitment

Ethical approval was granted by the University ethics committee. Recruitment of collaborators for the development project and participants for the pilot study followed a similar procedure. A senior worker acted as gatekeeper in each setting who nominated potential candidates fulfilling the inclusion criteria of having a recognised learning disability, the ability to understand single words (speech and/or sign), to see and recognise pictures; reliable use of ‘yes’ and ‘no’, and interest/willingness to take part in the project. Information about the project relevant to either collaborator or participant was presented in ‘easy read’ formats, employing simple language enhanced by clipart pictures. Supplementary verbal explanations were also given. Flexibility regarding a formal signature of consent was applied with some individuals writing their name and others drawing a mark indicating consent. Consent to act as a collaborator was checked with the TAG members at the start of each meeting. Similarly, ongoing checks were made with the participants during the Talking Mats® procedure for the pilot study. A unique identification number was assigned to each collaborator and participant to preserve anonymity.

Once consent had been achieved, a recruitment profile was completed on each collaborator and participant by a member of the research team in association with the relevant keyworker. The profile covered personal background information, rating of communication skills on a 6-point scale with associated descriptive summaries (as shown in table 1), descriptive summary of literacy skills and any associated difficulties. This information on the collaborators enabled the researchers to cater for individual needs and to facilitate their participation in the TAG meetings. For example, three of the collaborators (C2, C3 and C6) with communication skills ratings of ‘2’ experienced difficulties in understanding and expressing their views that required individual support at the meetings. In this way, a core group of six people was established at the day service and a supplementary membership of four people in a local respite service, who agreed to act as collaborators in Talking Mats Advisory Group (TAG). The supplementary membership was established for two reasons: 1. To recruit younger collaborators to complement the older members of the core group who were above the age of 40 years; 2. To provide a forum for review of decisions by the core group. Table 1 provides a summary of collaborator characteristics.

Table 1 Summary of collaborator characteristics for TAG

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Collaborator | Age | Sex | Factors | Communication (rating: 0-6) | Literacy  |
| C1 | Early 60’s | F |  | Generally clear speech. Some obvious difficulties with fluency of expression and facility of comprehension. (5) | Reads text in books & newspapers; writes letters & e-mails. |
| C2 | Mid-50’s | F | Uses a wheelchair & a walking frame | Fragmentary expression; great need for inference, questioning and guessing by listener. Limited exchange of information. (2) | No known or observed ability to read or write |
| C3 | Early 40’s | F |  | Fragmentary expression; great need for inference, questioning and guessing by listener. Limited exchange of information. (2) | No known or observed ability to read or write |
| C4 | Late 30’s | M | Uses an electric wheelchair | Unclear speech. Some obvious difficulties with fluency of expression and facility of comprehension. (5) | Not known |
| C5 | Late 50’s | M |  | Generally clear speech. Some obvious difficulties with fluency of expression and facility of comprehension. (5) | Not known |
| C6 | Mid 30’s | F | Uses hearing aids | Fragmentary expression; great need for inference, questioning and guessing by listener. Limited exchange of information. (2) | No known or observed ability to read or write |
| C7 | Mid 30’s | F | Uses hearing aids. | Clear speech. Minimal discernable communication difficulties. (6) | Reads text in books & newspapers; writes letters & e-mails. |
| C8 | Mid 30’s | F |  | Clear speech. Minimal discernable communication difficulties. (6) | Reads text in books & newspapers; writes letters & e-mails. |
| C9 | Mid 30’s | M | Attention problems; epilepsy. | Unclear speech. Some obvious difficulties with fluency of expression and facility of comprehension. (5) | Some social sight reading with pictorial support; copy writes simple words. |
| C10 | Mid 30’s | M | Thyroid condition – tires easily | Mainly clear speech with some sound errors. Minimal discernable communication difficulties. (6) | Some social sight reading with pictorial support; copy writes simple words. |

**Co-production of Talking Mats® interview**

The aims of the TAG were to: establish an appropriate vocabulary for talking about the topic of ‘television watching’; select the most meaningful and relevant graphic representations for vocabulary items; determine core topics that were relevant to television-viewing habits and preferences; and categorise television programmes in an accessible way.

The TAG core membership attended the same day service. They met six times during an eight-week period – each meeting lasting about 90 minutes. Collaborator attendance of the core TAG meetings varied between 2-6 people. One collaborator declined to continue her attendance after week 1 due to tensions with another member. The meetings were held in a separated area of the day centre with refreshments served at the midway point. All the meetings followed a similar format with the principal investigator leading and three student researchers providing support for individual members. The first part focused on generating vocabulary items for the topic of television-watching. The second part addressed the selection of graphic representations to be used in the Talking Mats procedure and the categorisation of television programmes into recognisable genres. Talking Mats® were used to help collaborators evaluate the graphic representations (good, ok, bad) and to sort the different programmes according to type. Notes, consisting of digital photographs of the Talking Mats completed and some supporting text were produced after each meeting. These were given out and reviewed at the start of each subsequent meeting.

TAG (supplementary) meetings started after the completion of TAG (core) ones. These were one-off appointments – two individual meetings and one paired meeting. The ‘supplementary’ meetings enabled the review of decisions and development work by the core TAG group through a series of planned activities, such as sorting programmes according to TV categories, generating additional vocabulary and rating graphic-representations.

* Vocabulary

In order to generate topical vocabulary for talking with the collaborators about television, a review of television schedules and associated literature published in national papers was carried out. The plethora of digital channels and the wide range of programmes meant it would have been impossible to generate symbols for all programmes. The scope was therefore set for the main terrestrial and Freeview channels. It was decided that blank cards would be available for hand-drawing representations of items from the wider digital channels as required.

To establish a working vocabulary for talking about television-viewing habits, core TAG members were invited to look at television magazines and to recall recent televisual entertainment. Discussions of time in relation to television-viewing were frequently related to concrete events. For example, routine activities such as ‘clean your teeth’ and ‘get dressed’ were linked to the morning time. In addition, the TAG (core) identified television programmes that they enjoyed and talked about recent programmes watched.

All topical vocabulary used by the collaborators was written verbatim, in situ. This was later uploaded to an interactive Wiki document as a cumulative record. The final Wiki consisted of 47 vocabulary items around the topic of television watching. The vocabulary was grouped under five categories; television-viewing equipment; people and places relevant to television-watching, food and drink; TV schedule times and associated events; and finally the names of television programmes. This revealed that the collaborators not only had a functional vocabulary but also a technical vocabulary, for example, ‘freeview’ and ‘flatscreen’. Conventional representation of time, e.g. clock faces and digital display of hours and minutes, seemed to confuse the collaborators. However, the use of routine events to indicate time of day, e.g. mealtimes, proved more successful. Out of the 138 programmes used in the draft Talking Mats interview for the pilot study, 89 programmes were identified by the TAG.

* Symbols

In order to establish the most recognisable set of symbols to represent the vocabulary items for use in the Talking Mats® interview, the TAG members were asked to review and evaluate different images for each item. Drawing on the vocabulary generated at each TAG meeting, the research team prepared symbols for subsequent meetings using Boardmaker Plus v.6 software (Mayer-Johnson, 2011). These included words associated with the Talking Mats procedure: rating scales (good-ok-bad; yes-maybe-no; like; not sure/don’t like); and words associated with viewing habits: frequency and time; and context for watching television.

The symbols were printed in colour, matt laminated with loop fasteners on the reverse side for adherence to the carpet mat. The main topics sourced by the vocabulary work were: ‘context for TV watching’, ‘time for TV’; and ‘Types of TV programme’. They were made into topic cards for the Talking Mats measuring 10x5cm with a pale blue background and thick, dark blue border. Individual item cards under each topic measured 2.5cm2, with a cream background and thick, black border. Some item cards had more than one graphic representation. Rating scale items were 8cm2 with coloured borders based on traffic lights: green for ‘yes/good/easy’; yellow-orange for ‘OK/maybe’ and red for ‘no/bad/difficult’.

The procedure for reviewing and evaluating the symbols entailed placing a carpet mat in front of each collaborator. The topic card was placed at the bottom - in the centre, with the rating scale placed across the top of the mat. The item cards for a topic were presented to each collaborator who placed it in relation to the three-point rating scale at the top of the mat on the basis of whether their response to the visual image on the card was ‘yes/good/easy’, ‘OK/maybe’ or ‘no/bad/difficult’. Group ratings were recorded, summarised and reviewed. Items that were rated as ‘no/bad/difficult’ were excluded and a revised symbol reviewed by the group. Only items rated as ‘yes/good/easy’ and ‘OK/maybe’ were included in the draft set of symbols to be used in the pilot study

* TV Genres

The television programmes had to be categorised in a way that was comprehensible to people with learning disabilities. This meant using concrete language to label the type of programme. Initially, the television genres used by the BBC were reviewed. The eleven categories listed were: children’s, comedy, drama, entertainment, factual, learning, music, news, religion/ethics, sports and weather. Five of the categories were considered too abstract, namely drama, entertainment, factual, learning, religion/ethics. Music as a separate category was deleted and subsumed within the new categories that were generated. Fourteen categories were established and labelled to capture the tangible qualities of the programmes they represented. The one exception was the first category – ‘Soaps’ – labelled by its familiar tag. Table 2 presents the fourteen categories of television programme with their indicative content.

Table 2 Categories for grouping television programmes

|  |  |
| --- | --- |
| **TV Genre** | **Examples of Programmes** |
| 1. Soaps
 | Eastenders, Coronation St; Neighbours |
| 1. Police, Hospital and Adventure
 | Inspector Morse; Casualty; Doctor Who |
| 1. Home, Garden and Cars
 | Top Gear; Love Your Garden |
| 1. Animals and Countryside
 | Countryfile; River Monsters |
| 1. Singing and Dancing
 | X Factor; The Voice |
| 1. Sports
 | Match of the Day; Snooker |
| 1. Comedy
 | Harry Hill; Mrs Brown’s Boys |
| 1. Chat Shows
 | Graham Norton; The One Show |
| 1. Children’s TV
 | In the Night Garden; Dennis and Gnasher |
| 1. Games Shows
 | Pointless; The Chase |
| 1. News and Politics
 | News; Weather; Panorama |
| 1. Real Life
 | Big Brother; Traffic Cops |
| 1. Long Ago
 | Antiques Road Show; Who do you think you are |
| 1. Cooking
 | Come Dine with Me; Great British Bake-off |

Each category was tested out by the collaborators in a series of card sorting exercises, such as: the person was given a category-topic card and had to claim appropriate individual items presented by the researcher; the person had to sort items into one of two topics displayed in the right and left hand corners of the mat; individuals were asked what programmes they could think of under each category-topic presented. The collaborators were able to use the categories effectively, although a few items were associated with more than one category. For example ‘Newsround’ featured in ‘Children’s TV’ as well as ‘News and Politics’. Such cases were noted and the identified symbols were included in all relevant categories.

* Script

A script to accompany the Talking Mats procedure was drafted using vocabulary from the Wiki document. The aim was to use simple sentence structures that could be processed by people with learning disabilities. The option for Makaton signed support for key words was inserted, accompanied by instructions for manipulating the materials during the procedure. The written content of the draft script was assessed for its syntactic properties using the Language Assessment, Remediation and Screening Procedure (LARSP) framework (Crystal *et al*. 1976; 81), which assigns utterances to age-related, developmental norms. There were 42 utterances at stage IV and below (age equivalent of 3;0 years and below), which was considered acceptable. However, 14 utterances fell into stage VI and above. These utterances were reviewed and simplified to correspond to a lower stage prior to the pilot study.

* Administration

The developed materials for the Talking Mats® interview was called the TeLeTiMe kit - a title that incorporated the objective of the interview procedure (**TeLe**vision viewing habits and preferences **T**alk**i**ng **M**ats int**e**rview). It was decided to introduce a trial mat prior to the introduction of the first topic in the TeLeTiMe survey, as recommended by Murphy & Cameron (2008). This was to orientate the respondent to the procedure. Four trial mats were developed for this purpose, containing simple questions with either absurd or correct response options. For example , one topic was ‘Things with Wheels’ with the options for consideration being ‘car’, bicycle’, ‘bus’, mobile phone’, ‘cake’ and ‘house’. As appropriate, the participants made a response of either ‘yes’ or ‘no’. These were trialled with the collaborators successfully.

The finished survey tool consisted of a script, carpet mat, clear plastic wallets containing graphic-representations labelled by topic. In addition, as advocated by Lewis (2004), a ‘don’t know’ option in the form of a labelled box was added to the kit, where the participant could discard an unknown item. Two rating scales were included according to the requirements of the topics. The full content of TeLeTiMe kit is shown in table 3.

Table 3 Structure and content of TeLeTiMe kit

|  |  |  |
| --- | --- | --- |
| **Topic** | **Indicative Content** | **Rating Scale** |
| Trial mats | Things to eat; Things to drink; Things with legs; Things with wheels | Yes; No |
| Mat 1. All about watching TV | People: parents; carers; friends; alone;Place: kitchen; bedroom; front roomActivities: eating; drinking; talking; being quiet | Yes; Sometimes; No |
| Mat 2. All about time for TV | Around mealtimes; parts of the day; days of the week | Yes; Sometimes; No |
| Mat 3. All about TV Programmes | Categories of TV programmes | Like;Ok/Maybe/Alright; Don’t Like |
| 4. Sub-mats (n=13): All about -each TV category | Individual programmes for each programme category | Like;Ok/Maybe/Alright; Don’t Like |

The entire kit was put together in a cloth bag for portability and displayed a ‘television’ logo for participant recognition, as illustrated in Figure 1.

Figure 1 TeLeTiMe kit using Talking Mats®

Administration manual with script

 

Wallets containing topic cards with options

Carpet mat showing rating scale

Blank cards for drawing own options

I don’t know box

**Pilot Study**

A pilot study was carried out to check the feasibility of the procedure and to identify necessary adaptations prior to the main study. A convenience sample of five adult participants with learning disabilities, aged 36;10-48;06 years. Two participants (P3 and P4) had acted as TAG (supplementary) members previously and were familiar with the concept of Talking Mats®. The three other participants (P1, P2 and P5) had no previous experience. Table 4 summarises the participant characteristics.

Table 4 Summary of participant characteristics for pilot study

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Participant | Age (yrs;mths) | Sex | Factors | Communication (rating: 0-6) | Literacy  |
| P1 | 39;00 | M | Tunnel vision; epilepsy | Generally clear speech. Some obvious difficulties with fluency of expression and facility of comprehension. (5) | Reads text in newspapers; unable to write. |
| P2 | 38;06 | F | Vision in one eye only. | Clear speech. Minimal discernable communication difficulties. (6) | Reads text in books & newspapers; writes letters & e-mails. |
| P3 | 36.10 | M | Attention problems; epilepsy. | Unclear speech to the unfamiliar listener due to phonological disorder. Some obvious difficulties with fluency of expression & facility of comprehension. (5) | Some social sight reading with pictorial support; copy writes simple words. |
| P4 | 37;06 | M | Thyroid condition – tires easily | Partially clear speech – contains some phonological errors. Minimal discernable communication difficulties (6) | Some social sight reading with pictorial support; copy writes simple words. |
| P5 | 48;06 | F | Arthritis affecting walking & general mobility. | Clear speech but with dysfluency characterised by blocking and initial syllable repetition. Minimal discernable communication difficulties (6) | Reads text in books & newspapers; writes letters & e-mails. |

The participants all lived at home with one or two parents and had been coming to the respite facility regularly for around 6 years. Four of the participants had Down syndrome. The aetiology of P3 was unknown. Their communication skills ranged from some obvious difficulties with fluency of expression or facility of comprehension (n=3) to minimal discernible difficulties (n=2).

* Procedure

The TeLeTiMe kit was administered in a quiet setting with minimal distractions. The Interviewer and the participant sat at right angles to one another at a table. The mat was placed in front of the participant and the TeLeTiMe kit was placed beside the interviewer. A digital camcorder was positioned on a tripod and focused on the dyad for later evaluation of the Talking Mats effectiveness. The order of the TeLeTiMe Talking Mats was followed as summarised in table 5. Although the draft script was adhered to as far as possible, there was still the opportunity for individuals to comment on the activity at any stage. Field notes were completed by the interviewer immediately after each procedure, which included observations of the participant’s general demeanour and comments on procedural aspects. After each core mat and sub-mat was completed, a digital still photograph was taken. Participants completed sub-mats on the different genres for which they had rated ‘like’ only. The photographs were collated into a personalised booklet that was given in a bound, hard copy to each participant at the end of the project.

* Evaluation

Two researchers independently evaluated the video footage on each mat and sub-mat completed. Using the format recommended by Murphy & Cameron (2005), a frequency rating scale (4-always; 3-often; 2-50:50; 1-occasional; 0-never) was used to consider five aspects of the procedure: the participant’s understanding of the issue for discussion, engagement with the interviewer, confidence, and satisfaction with the end result; and the interviewer’s understanding of the participant’s views. Thus a score of 20 would indicate the highest effectiveness rating possible. According to Murphy & Cameron (2005) a summative score of 12 and below has questionable effectiveness. The midway point between the two ratings was taken in each case.

**Findings**

The participants did one set up mat, with the exception of P1 who completed two. They all completed the three core mats (All about: watching TV; time for TV; different programmes). The number of sub-mats on the TV programmes under each genre depended on how many the participant rated as ‘like’ during mat 4. Different TV Programmes. P1 completed 13 out of 14 sub-mats; P2 completed 6; P3 and P4 both completed 8; and P5 completed the fewest at 5.

In total 61 completed Talking Mats were evaluated, including 40 sub-mats. Table 5 shows how this number was distributed across the different mats and sub-mats. Researcher evaluation ratings did not vary by more than 1 or 2 points. Scores ranged from 16-20 with an overall mean of 18.75, thereby demonstrating the effectiveness of the TeLeTiMe procedure.

Table 5 Distribution of completed mats with effectiveness ratings

|  |  |  |
| --- | --- | --- |
| Talking Mats by Topic (number completed) by participants | Mean  | Range |
| Set up  | Things with legs (2); Things to drink (4) | 19.75 | 19.5-20 |
| Core Mats | All about watching TV (5) | 18.6 | 17-20 |
| All about time for TV (5) | 18.5 | 17-19.5 |
| All about different programmes (5) | 18.1 | 16.5-19 |
| Sub-mats | Soaps (5); Police, Hospital & Adventure (3); Home, Garden & Cars (1); Animals & Countryside (4); Singing & Dancing (4); Sports (2); Comedy (4); Chat Shows (2); Children’s TV (1); Game Shows (5); News & Politics (2); Real Life (1); Long Ago (3); Cooking (3) | 18.8 | 16-20 |

Recorded observations of the completed Talking Mats® procedures related to three key areas: interview length; option cards; and currency of TV programmes.

* Interview length

The duration of the interviews ranged from 30-50 minutes depending on how many sub-mats were completed. Whilst all the participants demonstrated good attention for the activity and expressed their personal enjoyment, P1 seemed to tire during the procedure. His interview lasted the longest because he declared his ‘like’ of 13 TV genres, which meant completing 13 sub-mats! To limit the number of sub-mats, a star rating was introduced and trialled with the last participant (P5), who was invited to place a star next to her top three choices. This helped to limit the length of the interview whilst also identifying favourite TV genres. To counter lack of familiarity with the script and the materials, it was recommended that all interviewers receive training to ensure efficient and timely handling of the materials and adherence to the administrative procedure. In addition, the TV genres were reviewed to identify any possible mergers. The category ‘long ago’ contained the fewest options and was therefore subsumed within ‘’home, garden and cars’.

* Option Cards

Whilst ‘time for TV’ was represented by concrete daily events such as mealtimes, there was no consideration of frequency of TV watching. An option for ‘days of the week’ was recommended for the main study, whereby the respondent would simply identify the days on which they watched TV. Because of the success of introducing a star allocation system at the end of the TV genres mat, it was decided this should be made available at the end of each sub-mat so that the respondent’s most preferred programmes could be identified.

* Currency of TV programmes

Because of the ever-changing nature of TV programme schedules and the wide range of digital channels and programmes, the prepared options may lack currency for some respondents. This was addressed in the pilot study by inviting participants to draw their own representations on the blank cards. For the main study, it was recommended that during the data collection period television schedules be reviewed on a weekly basis. In addition, the current and previous week’s schedules should be available for reference during each TeLeTiMe procedure.

**Discussion**

Co-production involved working with an advisory group (TAG) comprising core members, followed up by meetings with supplementary members. Talking Mats® were used to empower the collaborators to evaluate the readability of graphic-representations. Vocabulary generated by the TAG was recorded in a Wiki document and informed script development to accompany the TM procedure. A LARSP (Crystal *et al*. 2005) analysis was performed on scripted utterances to ascertain their linguistic complexity and verify morphosyntactic accessibility. The resulting Talking Mats® procedure was piloted with five adults with learning disabilities. Effectiveness ratings for the completed mats were above the recommended minimum score of ‘12’ (Murphy & Cameron 2005).

* Co-production

Engaging in analytical work of this type is a challenge frequently identified for people learning with disabilities (Richardson & Le Grand 2002). The topic of television was familiar to the collaborators and a suitable focus for a co-production activity. The use of Talking Mats® and other visual resources facilitated collaborator input to the development work, ensuring that experience alone was not the only source of support (Ravensbergen & van der Plaat 2010). Furthermore, vocabulary generation and categorisation of TV programmes represented tangible activities for the TAG members, because it drew on their personal knowledge and experience (Brewster, 2004). Certainly, the language used was suggestive of their expertise in this area and of their technical vocabulary, e.g. ‘free view’. Importantly, the development process introduced reflexivity in relation to both the lexical content of the Talking Mats® and the way items were grouped (Durose *et al*. 2012; Orr & Bennett 2009). Thus the accompanying script to the procedure was not only informed by the TAG, but was validated by people with learning disabilities making it fit for purpose in larger scale survey.

The topic of ‘television’ and the associated vocabulary represented tangible concepts that were likely to form part of each respondent’s experience. The structure and the visual medium of Talking Mats® appeared to support collaborator engagement with the development work, echoing observations by Murphy and Cameron (2008). It is worth noting that the majority of the collaborators expressed a desire to participate in the pilot or main study at a later date. This may have been due to personal interest in the topic of television, or else their positive engagement with the visual materials, including the Talking Mats-based activities used in TAG meetings.

* Feasibility

The TeLeTiMe procedure was piloted with five participants. Effectiveness ratings of between 16 and 20 demonstrated that the participants were able to express their views on television through this medium, which is consistent with findings from other research using Talking Mats (Bell & Cameron 2007; Murphy & Cameron 2008). Any variation in individual ratings is probably attributable to the different abilities and personal factors of the participants. P5 achieved the highest mean score and was probably the most cognitively-communicatively able of the participants. P1’s interview lasted the longest time of all the participants - 45 minutes. The participant expressed a liking for 13 out of the 14 television genres and therefore completed the most sub-mats. In addition, his tunnel vision may have affected the effort required to complete the Talking Mats, making him tire towards the end of the interview. P3 experienced intelligibility problems and the visual medium seemed to contextualise and clarify his communications. Literacy skills were not a pre-requisite for a successful TM completion. Neither P3 or P4, who both had minimal literacy skills, were compromised in their ability to complete the TeLeTiMe procedure. Thus the TeLeTiMe kit, with the suggested amendments in place, was considered fit for purpose, echoing the findings of other studies employing Talking Mats with a similar population (Brewster 2004, Cameron & Murphy 2002; Germain 2004; Murphy & Cameron 2008, Murphy *et al*. 2005, Rabiee *et al*. 2004).

* Limitations

With regard to the development of the TeLeTiMe tool, TAG collaborators were recruited from the same day service and a respite service. Whilst convenient in the time scale, it was not representative of the adult population because it did not involve anyone below the age of 36 years. The dynamic of the core TAG group was affected by tensions between two of its members who simply did not like each other. It would have been better to check with the potential membership how they felt about working with each other and to set up splinter groups to avoid conflict between people. The pilot was conducted with a convenience sample. The participants had good communication skills and therefore the linguistic demands of the procedure were not tested out on less able individuals. Two participants had acted as TAG (supplementary) members and were not, therefore, naive to the Talking Mats® procedure.

**Conclusion & Implications**

Working with people with learning disabilities proved an effective way to develop a survey tool for investigating the television viewing habits and preferences of adults with learning disabilities. Their involvement ensured both the selection of appropriate and meaningful vocabulary items for talking about the topic and the images to represent them. At an organisational level, the collaborators were able to provide useful feedback about the workability of the topic categories and their content. Six meetings were held of the core group, which allowed for group relationship building and the progression of the task. The supplementary membership proved helpful in reviewing the decisions made by the core group. Thus co-production is not only possible, but essential to the development of a survey tool to be used on the wider population with learning disabilities. However, preparation of visual supports and relevant activities to support the development is critical. The pilot of the TeLeTiMe tool demonstrated the feasibility of the procedure, whilst identifying some key recommendations for address in the main study. The final survey will be reported at a later date.

**References**

Abudarham, S. (2002) Assessment and appraisal of communication needs. In: Abudarham, S., Hurd, A. (Eds.) *Management of Communication Needs in People with Learning Disability.* London, Whurr publishers: 33-81.

Ajodhia-Andrews, A. & Berman, R. (2009) Exploring school life from the lens of a child who does not use speech to communicate. *Qualitative Enquiry*,**15**: 931-951.

Baxter, V. (2005) Learning to interview people with a learning disability. *Research Policy and Planning,* **23**: 175-180.

BBC. *iPlayer: TV*. Available at: <http://www.bbc.co.uk/iplayer/tv> (last accessed on 12 December 2015).

Beart, S., Hawkins, D., Kroese, B. S., Smithson, P., & Tolosa, I. (2001). Barriers to accessing leisure opportunities for people with learning disabilities. *British Journal for Learning Disabilities,* **29**: 133-138.

Bell, D. M. & Cameron, L. (2007) From dare I say...? to I dare say: A case example illustrating the extension of the use of Talking Mats to people with learning disabilities who are able to speak well but unwilling to do so. *British Journal of Learning Disabilities,* **36**: 122-127.

Boyle, D., Clarke, S. & Burns, S. (2006a) *Aspects of Co-production: the Implications for Work, Health and Volunteering.* London, New Economics Foundation.

Boyle, D., Clarke, S. & Burns, S. (2006b) *Hidden Work: Co-production by People Outside Paid Employment.* London, Joseph Rowntree Foundation.

Brewster, S.J. (2004) Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities*, **32**: 166-169.

Broadcasters' Audience Research Board (BARB) (2012-14) Trends in Television. Annual reports. Available at: www.barb.co.uk (last accessed on 12 December 2015).

Broadcasters' Audience Research Board (BARB) (2008) *People with Learning Disabilities and Communication Services*. Ofcom Communication Services.

Bunning, K. (2011). Let me speak – facilitating communication. In: Atherton, H.L., Crickmore, D.J. (Eds.) *Learning Disabilities Toward Inclusion. 6th Edition.* London, Elsevier Churchill Livingstone: 91-111.

Bunning, K., Health, B., & Minnion, A. (2009) Communication and empowerment: A place for rich and multiple media? *Journal of Applied Research in Intellectual Disabilities,* **22**: 370-379.

Buttimer, J. & Tierney, E. (2005) Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities*, 9, **25**: 25-42.

Cameron, L., & Murphy, J. (2002) Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities,* **30**: 105-112.

Cameron, L., Watson, J. & Murphy, J. (2004) Talking Mats: a focus group tool for people with learning disability. *Communication Matters,* **18**: 33-35.

Clarke, C.L., Lhussier, M., Mino, C., Gibb, C.E. & Perini, T. (2005) Paradoxes, locations and the need for social coherence: a qualitative study of living with learning difficulties. *Disability & Society* **20**: 405-419.

Crystal, D., Fletcher, P. & Garman, M. (1976) *The Grammatical Analysis of Language Disability: A Procedure for Assessment and Remediation.* London, Edward Arnold.

Crystal, D., Fletcher, P., & Garmin, M. (1981 revision). *Language Assessment, Remediation and Screening Procedure, LARSP. Linguistic Profile Charts, 1*. University of Reading.

Durose, C., Beebeejaun, Y., Rees, J., Richardson, J. & Richardson, L. *Connected Communities: Towards Co-Production in Research with Communities.* Connected Communities

Emerson, E., Malam, S., Davies, I. & Spencer, K. (2004) *Adults with Learning Difficulties in England 2003/4.* NHS Health and Social Care Information Centre.

Germain, R. (2004) An exploratory study using cameras and talking mats to access the views of young people with learning disabilities on their out-of-school activities. *British Journal of Learning Disabilities,* **32:** 170-174.

Hibbard, J.H., Mahoney, E.R., Stock, R. & Tusler, M. (2007) Do increases in patient activation result in improved self-management behaviors? *Health Services Research* **42***:* 1443-1463.

Jones.F.W., Long, K. & Finlay, W.M.L. (2006) Assessing the reading comprehension of adults with learning disabilities. *Journal of Intellectual Disability Research,* **50**: 410-418.

Law, J., Bunning, K., Byng, S., Farrelly, S., Heyman, B. (2005) Making sense in primary care: levelling the playing field for people with communication difficulties. *Disability & Society*, **20**: 169-184.

Lewis, A. (2002) Accessing, through research interviews, the views of children with difficulties in learning. *Support for Learning,* **17**: 110-116.

Lewis, A. (2004) 'And when did you last see your father?' Exploring the views of children with learning difficulties/disabilities. *British Journal of Special Education,* **31**: 3-9.

Lewis, A., Newton, H. & Vials, S. (2008) Realising child voice: the development of cue cards. *Support for Learning*, **23**: 26-31.

Mayer-Johnson (2011) *Boardmaker R v.6 - UK Edition*. Retrieved May 07, 2012, from Mayer-Johnson: http://www.mayer-johnson.co.uk/

Murphy, J. (2006) Perceptions of communication between people with communication disability and general practice staff. *Health Expectations,* **9**: 49-59.

Murphy, J., & Cameron, L. (2005) *Talking Mats: Coding Framework for Evaluation*. Stirling University.

Murphy, J., & Cameron, L. (2008). The effectiveness of Talking Mats with people with intellectual disability. *British Journal of Learning Disabilities,* **36**: 232-241.

Nind, M. (2008) *Conducting Qualitative Research with People with Learning, Communication and Other Disabilities: Methodological Challenges*. ESRC National Centre for Research Methods.

Orr, K.M. & Bennett, M. (2009) Reflexivity in the co-production of academic-practitioner research. *Qualitative Research in Organisations and Management*, **4**: 85-102.

Purcell, R. (2009) Images for change: community development, community arts and photography. *Community Development Journal,* **44**: 111-122.

Rabiee, P., Sloper, P., & Beresford, B. (2004). Doing research with children and young people who do not use speech for communication. *Children & Society,* **19**: 385-396.

Ravensbergen, T. & van der Plaat, M. (2010) Barriers to citizen participation: the missing voices of people living with low income. *Community Development Review*, **45**: 389-403.

Realpe, A. & Wallace, L.M. (2010) *What is Co-production?* London, The Health Foundation.

Richardson, L. & Le Grand, J. (2002) Outsider and insider perspective: the response of residents of deprived neighbourhoods to academic definition of social exclusion. *Social Policy and Administration*, **36**: 496-515.

Robinson, J. & Tansey, J. (2006) Co-production, emergent properties and strong interactive social research: the Georgia Basin Futures Project. *Science and Public Policy*, **33:** 151-160.

Verhoeven, L. & Vermeer, A. (2006) Literacy achievement of children with intellectual disabilities and differ ring linguistic backgrounds. *Journal of Intellectual Disability Research,* **50**: 725-738.

Whitehurst, T. (2006). Liberating silent voices- perspectives of children with profound & complex learning needs on inclusion. *British Journal of Learning Disabilities,* **35**, 55-61.

Windrum, P. (2014) Third sector organizations and the co-production of health innovations. *Management Decision*, **52**: 1046-1056.

Young, L, Moni, K.B, Jobling, A and Kraayenoord, C.E. (2004). Literacy Skills of adults with intellectual disabilities in two community-based day programmes. *International Journal of Disability, Development and Education,* **51**: 83-97.

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